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ABSTRACT

This study examined the characteristics of elderly persons receiving help from family members as reported in published studies on family caregiving. The data were drawn from 10 volumes of the "Journal of Gerontology" and "The Gerontologist" (1978-1988). Thirty-one family caregiving studies were identified. Although few of the elderly require assistance with the activities of daily living, the data showed that family caregiving studies focused disproportionately on this severely disabled group. An analysis of the studies revealed that dementia and severe physical limitations were over-represented while less severe limitations were under-represented. Although the vast majority of family caregivers spend their time helping the elderly with transportation, shopping and errands, household chores, and meal preparation, this type of instrumental care was underrepresented in the literature. Family caregiving research appears to understate the most frequent help given to elders (instrumental help) and may over-represent caregiving burden. (Author/NB)

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Sampling Bias in Family Caregiving Studies: A Research Note[1]

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Abstract

This study investigated the characteristics of elderly persons receiving help from family members in published studies on family caregiving. The data were drawn from 10 volumes of the **Journal of Gerontology** and **The Gerontologist** (1978-1988); 31 family-caregiving studies were identified. Dementia and severe physical limitations were over-represented in these studies while less severe limitations were under-represented. Family caregiving research understates the most frequent help given to elders (instrumental) and may over-represent caregiving burden.

Key Words: care needs, dementia, personal care, instrumental care

Sampling Bias in Family Caregiving Studies: A Research Note

As the population aged 65 and older has grown, there has been increasing attention to the study of family caregiving; that is, spouses, children, and other relatives providing assistance to the elderly who require it. In fact, so much attention has been given to this area, a well-known gerontologist recently stated that the fact "that caregiving is stressful is now well-established" (Zarit, 1989, p. 147), and thus further descriptive studies of "stress and caregiving" probably are not needed.

But has the published literature represented the range of activities that occur under the rubric of family caregiving? The limitations of the elderly who require assistance extend from minor to severe and the corresponding help needed from minimal to total. Some individuals have severe health problems and require assistance with tasks such as eating, mobility, and bathing; tasks known as the Activities of Daily Living (ADL). Others require help, but their needs are less severe. They may need assistance with household tasks, cooking, shopping, and similar activities, tasks known as the Instrumental Activities of Daily Living (IADL). Has the family caregiving literature over-represented ADL limitations and underrepresented IADL limitations? If so, there may be two possible consequences: (a) the literature has overstated the amount of ADL help provided by family members while simultaneously understating the amount of IADL help, and (b) the literature has overstated caregiving stress or burden.

Nationally representative data (Shanas, 1979) indicate that the proportion of bedfast, housebound, or mobility-limited elderly in the United States is only around 14%. The most frequent areas in which the elderly need assistance are shopping and transportation (Bould, Sanborn, & Reif, 1989; Stone, Cafferata, & Sangl, 1987). The 1984 Supplement on Aging to the National Health Interview Survey (Spitze & Logan, 1989) demonstrated that only 6% of those 65 and older receive ADL help. While the need for ADL assistance is more evident in individuals aged 85 or older, only 15.7% of this age group needs assistance bathing and less than 1 in 4 (23.5%) needs assistance walking

(Spitze & Logan, 1989). Although ADL problems exist for a significant number of the elderly, the vast majority of older persons are independent with regard to ADL.

This paper investigates the characteristics of elderly persons receiving help from family members in family caregiving studies. We hypothesize that serious physical and cognitive limitations are over-represented in these studies, while minor physical and cognitive limitations that also result in care-receiving are under-represented.

Sample

The data for this study were drawn from the 10 volumes of the Journal of Gerontology (volumes 33 to 43) and The Gerontologist (volumes 18 to 28) published between 1978 and 1988. Each issue of each journal was examined to identify studies on family caregiving. In each family-caregiving study, descriptive data on care receivers were drawn primarily from the sample section but were also taken from the results and discussion sections depending upon where the information appeared. These data included the relationship of the caregiver to the care receiver (e.g., spouse, child), sample size, and the care receivers' care needs and/or health problems. Although the different studies rarely used the same measures of physical and cognitive impairment, most provided sufficient information to identify the nature of assistance needed.

Several criteria were used to identify articles for in this review. Articles were included that described actual caregiving by family members to elders in need of instrumental and/or personal care. Four types of articles were not included: (a) those which focused on attitudes toward caregiving or filial responsibility (Brody, 1981; Brody, Johnsen, & Fulcomer, 1984; Cicirelli, 1988; Finley, Roberts, & Banahan, 1988; Gelfand & Fandetti, 1980); (b) descriptions of social interactions or support that did not involve caregiving (Bankoff, 1983; Johnson, 1978; Koh & Bell, 1985; Moss, Moss, & Moles, 1985; Taylor, 1985; Weeks & Cueller, 1983; Wells & McDonald, 1981; Wolf, Breslau, Ford, Ziegler, & Ward, 1983; Yu & Wu, 1985); (c) policy

discussions, essays, or reviews that did not include a description of a sample (Brody, 1985; Jarrett, 1985; Kingson, 1988; Linsk, Keigher, & Osterbush, 1988; Silliman & Sternberg, 1988; Wisensale, 1988); and (d) those which primarily described interventions or evaluations of programs for caregivers or care receivers (Aronson, Levin, & Lipkowitz, 1984; Cohen, 1983; Crossman, London, & Barry, 1981; Fengler & Goodrich, 1979; Glosser & Wexler, 1985; Goodman & Pynoos, 1988; Halpert, 1988; Hartford & Parsons, 1982; Lazarus, Stafford, Cooper, Cohler, & Dysken, 1981; Liptzin, Grob, & Eisen, 1988; Pinkston & Linsk, 1984; Safford, 1980; Schmidt & Keyes, 1985; Shulman & Mandel, 1988; Winogrond, Fisk, Kirsling, & Keyes, 1987). Brody, Poulshock, and Machiocchi's (1978) study was difficult to classify. It was excluded, however, because it focused primarily on the presence of a family as a buffer to institutional placement and did not describe family caregiving.

Extent of Care Needs or Dementia

Studies of family caregiving rarely use identical measures to assess care needs. Of the 31 studies described here, 26 used different measures of assessment. Still, most reported sufficient information about caregiving activity to determine the level of care needs. Our aim was to identify whether care receivers required ADL assistance regardless of their need for IADL aid.

Several researchers assessed ADL needs with standardized measures (e.g., Brody & Schoonover, 1986; Cantor, 1983; Pearson, Verma, & Nellett, 1988). Other researchers developed their own measures to assess ADL needs (e.g., Barusch, 1988; Deimling & Bass, 1986; Horowitz, 1985). Still others reported the percentage of individuals requiring particular types of help (e.g., Shanas, 1979). A number of researchers indicated the health conditions of the care receivers or particular problems faced by the caregiver (e.g., Chenoweth & Spencer, 1986; George & Gwyther, 1986; Miller, 1987; Quayhagen & Quayhagen, 1988). Finally, several researchers indicated the number of hours of caregiving required per day or week (e.g., Hooyman, Gonyea, & Montgomery, 1985).

To keep from biasing the results, we employed conservative measures in determining the level of assistance required. Any study in which one of the following conditions were met was identified as representing ADL needs: (a) mean scores of 1 or greater on an ADL scale which assessed need for help with bathing, dressing, eating, mobility, transferring, and toileting; (b) indications that over half of the sample was severely or seriously impaired as assessed by a standardized impairment index (e.g., Cantor, 1983: 73% of the care receivers severely impaired on the Townsend Index of Functional Incapacity, Shanas, 1968); (c) mean hours of care needed/day greater than 10; (d) indications that at least 25% of the caregivers had difficulty providing a type of ADL care or a level of care (e.g., Chenoweth & Spencer, 1986: 25% of the caregivers reported that providing constant care was a problem); and (e) indications that at least 30% of the sample required ADL help (e.g., Johnson, 1983: 36% of the care receivers were severely impaired and required round-the-clock care). The criterion for inclusion in the dementia category was that a portion of the sample had dementing illnesses, for example, Alzheimer's Disease or multi-infarct dementia.

Studies in which none of these conditions were met were identified as excluding ADL care needs and/or dementia (e.g., Brody & Schoonover, 1986: mean = 10.6 hours of personal care/week; Rakowski & Clark, 1985: care receivers were judged by nurses to need continued help; Robinson, 1983: 71.2% independent on ADL measures; Scharlach, 1987: required assistance with not more than one physical ADL; Soldo & Myllyloma, 1983: at least moderate assistance with ADL or mobility; Strong, 1984: care receivers had chronic illness or disability; Townsend & Poulmock, 1986: mean personal care and/or ADL = 3.8.

Results

Over the 10-year period, 31 family-caregiving studies were published in the 2 journals. Four articles of the 31 utilized a data set for a second or third time. All but 3 of the 31 articles, 90.3%, were published in The Gerontologist. In 6 (19.4%) of the 31 studies, dementia was not mentioned but

care receivers received levels of ADL help that met the criteria stated above as indicative of at least moderate or higher levels of care need in the sample. (See Table 1.) In 8 (25.8%) of the 31 studies, dementia and moderate or higher ADL care needs were found in the study samples. Five (16.1%) of the 31 studies did not describe ADL needs but identified the sample as dementia patients. Thus, 19 (61.3%) of the family caregiving studies published between 1978 and 1988 in the two journals focused on samples which were moderately or severely impaired in terms of ADL needs and/or cognitive functioning. This proportion is conservative given the number of studies that may have included heavy care needs or dementia but which were not categorized as such because of vague or insufficient sample descriptions.

Table 1 about here

Discussion

Although few of the elderly require assistance with the activities of daily living (Shanas et al., 1968; Bould et al., 1989; Stone et al., 1987), data presented here show that family caregiving studies focus disproportionately on this severely disabled group. The vast majority of family caregivers in the United States spend their time helping the elderly with transportation, shopping and errands, household chores, and meal preparation. Yet this type of instrumental care provided by family caregivers is underrepresented in the literature which describes the dimensions and dynamics of caregiving. Over sixty percent of the family caregiving studies focus their attention on family caregivers who help the elderly who suffer from dementia and/or who need assistance to bathe, dress, eat, walk, move from a bed to a chair or the reverse, or use the bathroom. Such tasks are both essential and likely to be more difficult or onerous for caregivers to perform. This type of caregiving may indeed be stressful. It is not known, however, whether similar stresses are incurred by caregiving to individuals whose needs are instrumental.

An additional problem identified in the literature is the disproportionate emphasis on caregiving to the elderly with dementia. While only 10% of those 65 and older evidence any indication of dementia ("Fighting Off," 1981), over forty percent of the studies published over the 10-year period included dementia care receivers. Because caregiving to dementia patients has been shown to be more burdensome than caregiving to physically-impaired individuals (Birkel, 1987), family caregiving studies may thus over-represent caregiving burden. A related problem is the positive correlation between ADL limitations and cognitive functioning (Hansson & Remondet, 1988). The over-representation of severe physical impairments in family-caregiving studies suggests that cognitive impairments are represented in those caregiving studies as well.

Of course, studies on family caregiving to the severely-impaired and to the elderly with dementia are needed. The entire range of family caregiving, however, must be represented in research. The family caregiving process should be conceptualized as one in which care receivers--a minority of the elderly population--experience limitations that are offset by assistance from family members. In most instances, these limitations restrict a person's ability to shop, clean, cook, and complete similar tasks essential to life. Less commonly, these limitations also restrict a person's ability to bathe, dress, eat, and complete other personal care tasks also essential to life. Only when the total domain of family caregiving is represented in the literature will we be able to understand fully this phenomenon. Future research in family caregiving should respond to recent calls for more sophisticated, multivariate models that examine caregiving longitudinally (Zarit, 1989). In addition, research must examine more closely the full range of what it means to give care to persons with widely different needs and disabilities (Silliman & Sternberg, 1988). Only then will gerontologists be able to comprehend the factors that exacerbate or buffer the potential stresses of caregiving.

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Table 1

Care Needs of Care Receivers in 31 Family Caregiving Studies

Author(s)	Caregivers	N	Care needs/condition
A,*Barusch (1988)	spouses	89	53% dementia; mean number of (the following) areas of help = 1.5: 44% bathing; 29% dressing; 21% transferring; 16% toileting; 15% walking; 11% eating; 11% continence care; minimum of 20 hours of care/week
*Brody et al., 1987	married daughters	150	$\underline{M}$ = 21.4 hours of care/week from daughters; $\underline{M}$ = 35 hours from all sources; 85% help with shopping or transportation; Multilevel Assessment Instrument (MAI; Lawton et al., 1982) Personal Self Maintenance Assessment (PSMA: eating, dressing, bathing, grooming, getting in and out of bed, moving around the house) and in IADL (housework, laundry, cooking, house repairs, using the telephone, financial management, taking medicine, shopping, and transportation) across 4 daughters' employment groups; lower scores indicate more help needed; PSMA ranged from 15.2 to 17.3 (possible range = 6-18); IADL ranged from 14.95 to 20.74 (possible range = 9-27); 10-item Mental Status Questionnaire (Kahn et al., 1961) scores ranged from 6.1 to 7.9 (10 is highest competence)
*Brody & Schoonover (1986)	married daughters	150	52% personal care, $\underline{M}$ hours/week = 10.6; 55.3% meal preparation, $\underline{M}$ hours/week = 8; 73% housework/laundry, $\underline{M}$ hours/week = 7.2; 90.0% shopping/transportation, $\underline{M}$ hours/week = 4.8; MAI/PSMA $\underline{M}$ = 25 (possible range = 9-27); MAI/IADL $\underline{M}$ = 13 (possible range = 6-18); and in shopping/transportation, $\underline{M}$ = 4 (range = 3-6) (See Brody et al., 1987)
*Cantor (1983)	spouses, children, other	111	half acute medical crisis, half chronic care needs; 73% severely impaired; 15% seriously impaired; 12% some or mild impairment on the Townsend Index of Functional Incapacity (Shanas, 1968)

[A,B]Caserta et al. (1987)	spouses, children, other	888	dementia, 69% probable Alzheimer's; 50% 16 hrs of care/day; M = 46.4 (range = 23 (least impaired) - 80) on the Functional Dementia Scale (Moore et al, 1983), which assesses impairment in ADL, affect, and orientation
[A,B]Chenoweth & Spencer, (1986)	spouses, other	289	all but 8.3% Alzheimer's; 55% in nursing homes or other institutions; 25% reported that providing constant care was a problem
[A,B,D]Deimling & Bass (1986)	spouses, daughters	586	M = 3.1 of 6 ADL; 30% dependent in 5 or 6 areas (bathing, dressing, toileting, self feeding, and 2 in-house mobility tasks; some dementia; Mental Status questionnaire (3 scales from 0 (low) - 10): M = 3.4 Cognitive Incapacity, 7.5 Social Functioning, and 1.9 Number of Disruptive Behaviors
[A,B]Fitting et al. (1986)	spouses	54	dementia; 38.9% memory impaired, some supervision, self-care preserved; 24.07% language and/or praxis impaired, supervision necessary, some ADL aid; 37.0% global impairment, incontinence and/or gait disorder, total ADL assistance required (derived from Sjogren et al., 1952)
[B]George & Gwyther (1986)	spouses, children, other	510	Alzheimer's or related disorder; 34% institutionalized
Hasselkus (1988)	spouses, daughters other	15	Daily personal and/or instrumental care

Hooyman et al. (1985)	children other	80	assessed 21 tasks in 4 groups; M hours/month (continued, discontinued chore service clients), personal care = 9, 4; household tasks = 14, 13; community tasks = 20, 12, and psychosocial tasks = 38, 40
[A]Horowitz (1985)	children	203	M = 23.7 on a 12-item scale: 2 contact items ranging from 1 (<1/month) to 7 (> daily) and 10 extent of help items ranging from 1 (none) to 5 (at least 1 hr daily): transportation (71% received help), household chores (54.2%), shopping (84.7%), meal preparation (50.4%), personal care (30.5%), health care (32.1%), financial management (67.2%), linkage with formal services (74.0%), emotional support (91.6%), and financial aid (50.4%); "at least moderately impaired in ADL functioning" (p. 614)
[A,C]Johnson (1983)	spouses, children, other	167	Only 19% no ADL help (transportation, housekeeping, budget management/bureaucratic linkages, meal preparation, shopping, personal hygiene); 22% limited (1-3 ADL); 22% moderately impaired (4 or more ADL); 36% severely impaired, required round-the-clock care
[A,C]Johnson & Catalano (1981)	spouses, siblings, other	167	Acute care needs; post-hospitalization
[B]Miller (1987)	spouses	15	2/3 Alzheimer's; 1/3 other brain dysfunction; some physical deterioration, typically an arthritic condition
[A,B,B]Noelker (1987)	spouses, children	559	some dementia; 53% incontinent; M = 3.2 of 6 Personal Care Dependencies (i.e., bathing, dressing, grooming, toileting, transferring; feeding); M = 3.4 of 10 Signs of Cognitive Impairment (e.g., confusion); M = 1.8 of 10 on the Number of Disruptive Behaviors (e.g., interfering); SCI and NDB scoring systems: 0 (not at all), 1 (somewhat), 2 (great deal)

[c]Pearson et al., (1988)	spouses, children, other	46	24% possible dementia; 54% depression; other related diagnoses; varying amounts of help needed with 8 ADL and 9 IADL (Katz & Akpom, 1976); more instrumental needs; Mini-Mental State Examination (Folstein et al., 1975) M = 22.9 (range = 8 (more impaired) - 28); 30% mild impairment, 14% significant impairment; M = 14 on the Geriatric Depression Scale (Yesavage et al., 1983); range = 1 (low) to 28; Mental Status (Deimling & Bass, 1984), M = .67 disruptive behaviors (See Deimling & Bass, 1986)
[a,b,c]Poulshock & Deimling (1984)	spouses, children, daughters-in-law	614	some dementia; M = 3.05 of 6 ADL (bathing, dressing, toileting, mobility, incontinence, and eating); 30% needed help in 5 of the 6 areas; 50% had 3 or more symptoms of cognitive incapacity; 33% reported 2 or more disruptive tasks; M = 1.02 cognitive incapacity, 3.04 sociability, and 1.02 disruptive behavior (scales from 0 (low) to 4
[c]Pratt et al. (1987)	spouses, other	116	dementia
[a,c]Quayhagen & Quayhagen (1988)	spouses, daughters	58	Alzheimer's; M = 73.4 on the 29-item Memory and Behavior Problems Checklist (Zarit et al., 1980); individuals reported the following stressful behaviors: difficulty bathing (67.2%); difficulty cooking (62.1%); difficulty staying alone (62.1%); incontinence (56.9%)
Rakowski & Clark (1985)	spouses, children, other	90	receiving assistance for at least 6 months; judged by nurses to need continued help; M # of health problems that create the need for assistance is 2 to 3; none terminally ill or bedfast; no dementia; M = 10.3 areas mentioned by caregivers in which care was provided
Robinson (1983)	spouses, other	85	heart disease or hip surgery; 71.2% independent on ADL (Katz et al., 1970); 88.1% intact functioning on the Short Portable Mental Status Questionnaire (Pfeiffer, 1975)

Robinson & Thurnher (1979)	children	49	45% mentioned health problems; 27% mentioned cognitive problems; 45% mentioned assisting parents with physical or psychological disabilities
Scharlach (1987)	daughters	40	required assistance with not more than 1 physical ADL (bathing, eating, mobility); many needed help with IADL (housecleaning; shopping)
Shanas (1979)	spouses, children, other	7,660	total sample: 3% bedfast, 7% housebound; interviewed sample (n = 100): 2% bedfast, 5% housebound; 7% active only with difficulty
Soldo & Myllyluoma (1983)	spouses, children, other	2,338	at least moderate assistance with either the ADL or mobility; a minimum of 8 points on the 14-point Need For Assistance Scale (Soldo & Mossey, 1981)
*Stone et al. (1987)	spouses, children, other	1,924	aid, directive assistance, or supervision with bathing, dressing, feeding, transferring, toileting, mobility (see Liu et al., 1985); 2.8% IADL only; 31.6% 1-2 ADL; 23.2% 3-4 ADL; 42.4% 5-6 ADL; 80% daily assistance, M = 4 hours/day; 67% personal hygiene; 46% mobility
Strong (1984)	relatives	20	Chronic illness or disability
Townsend & Poulshock (1986)	children	101	M personal care and/or IADL = 3.8 (range = 1-13); 43% have "physical health problems (that) interfered a great deal with their ability to do things for themselves" (p. 103)

[a]Zarit et al. (1980)	spouses, daughters	29	senile dementia; M = 2.4 of 21 Physical ADL scale (e.g., dressing, walking; Lawton, 1971); M = 10 of 24 IADL scale (e.g., using the telephone; Lawton, 1971); "substantially impaired in many areas" (p. 652); 2/3 required some IADL help; M = 6.4 incorrect of 10 items on the Mental Status Questionnaire (MSQ; Kahn et al., 1960); M = 8.3 incorrect of 16 items on the Face-Hand Test (FHT; Kahn et al., 1960); M = 18.6 incorrect of 30 items on the mental status test (Jacobs et al., 1977); Memory and Behavior Problems Checklist (16 problems; rated from 0-never to 4-daily or more often): 62% indicated that 4 or 5 memory problems occurred in the last month; 18% 3 or more behavior problems occurred in the last month; 34% reported restlessness and neglecting self care
[b]Zarit et al. (1986)	spouses	64	Alzheimer's Disease (2/3) or dementia (1/3) according to DSM III criteria; husbands' M = 54.05 and wives' M = 38.82 on the 28-item Memory and Behavior Problems Checklist (Zarit et al., 1980); ADL deficits more prominent at 2-year follow-up; number correct on 10-item MSQ (Kahn et al., 1960) items: husbands' M = 4.70, wives' M = 1.97; number of correct FHT (Kahn et al., 1960) items: husbands' m = 8.27; wives' m = 4.03 (See Brody et al., 1987)

[a]Study classified as focusing on an ADL-impaired sample.

[b]Study classified as focusing on a dementia sample.

[a,b]Studies with matching lower-case superscripts used the same data base.

ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living